## National Webinar Transcript

August 20, 2021

Presented by:



This program was made possible with support by:









Melissa Rosen:

Welcome everybody. Welcome to Sharsheret's Shalom Shabbat program. I am going to stop the share so you can see us. Perfect. Welcome. My name is Melissa Rosen and I'm the director of training and education at Sharsheret. And I want to thank my colleagues, Rachel Teisha and Sarah Eagle for being here today to make this program run smoothly and be a success. We are always grateful for an opportunity to reconnect with you and to recenter. And we've found, and I'm sure you have too, that as we deal with this ongoing and as it appears renewed isolation during this difficult time, these opportunities are more important than ever. Before we get going, just a few housekeeping notes. I want to thank our sponsors for today's program. ASI, GSK, Susan G Komen of greater New York City, Merck and [inaudible 00:01:13].

You may have noticed you were muted on today's program. Please stay on mute so that you can clearly hear today's presenters. As always, and I saw there've been a couple of questions about this already, this program will be recorded. Of course, no faces or names will be on the recording, but if you wish to turn your video off for privacy now, that option exists. You can do that by clicking the dots next to your square, and you can choose to rename yourself that way as well. And that's an easy way to do that. You will be notified when the recording and the transcript of today's program is posted on the Sharsheret website. Please feel free to share that link with anyone who may be interested. Shalom Shabbat, however you celebrate and whatever your experience with Shabbat is or has been, we can all use an opportunity to recenter ourselves in the midst of treatment, survivorship, the pandemic, or honestly just the normal chaos of a life well lived.

And that's what today is all about. Together, we'll explore different paths to healing, including song and poetry and how they can enhance both Shabbat and life as a whole. And we'll each come away with a bit of inspiration for the week ahead. As I've mentioned in previous programs, there's always some level of chaos in life. Work, family, volunteer commitments. And of course, for those of us who have faced cancer or are dealing with survivorship, there's even more chaos. There really is. Physical, emotional, even spiritual. We all need a break. We need an opportunity to take a deep breath. It's absolutely critical for not only our health, but also our happiness. And yet, in addition to all this chaos, the world has given us an opportunity to take a breath from it. A mandatory pause. By the way, mental health professionals have recommended taking time to pause from normal life on a regular basis.

And the Jewish tradition gives us just that, a weekly pause. Simply an opportunity to rest and regroup each week. To focus on what's important and what gives our lives meaning. And that's different for each one of us on the screen today. Could be family, health, something else entirely. And how we celebrate that pause or recognize that pause is different for each of us too. Some of us celebrate traditionally. Others have found innovative ways to make Shabbat meaningful. Some prepare elaborate meals, others choose takeout, dinner or pizza as a break in cooking. Some attend services, at least when we can and we're not in a pandemic. Others spend time in nature or specifically

plan family activities. Each person celebrates in a way that is meaningful to them. And that makes us a beautiful, a beautiful collaborative group in front of us.

But I wanted to encourage no matter what you do, each one of us to mark this time. Whether this is something you do every week, something you're just exploring now, whether you celebrate traditionally, whether you find some amazing, innovative way to mark the day, it's important to take that time, to make ourselves and our families a priority.

I want to encourage you to give yourself the gift of that time, dedicated to renewal. Okay. I am actually so incredibly pleased to introduce today's guest, Maya Bernstein. Maya is a breast cancer survivor herself, and a Sharsheret caller. She teaches leadership and facilitation at Georgetown University and also teaches at Yeshivat Maharat. Maya is a singer, a songwriter, and a poet, as you will see today. She will be sharing two of her poems and one of her songs with us. She will also be speaking about how music and writing were an unexpected source of healing for her. Maya, welcome, and the floor is yours.

Maya:

Thank you, Melissa. Thank you, Rachel and Sarah and Sharsheret. I'm going to start by sharing a poem called I'm Tired of Terror and Despair. And before I share it, I'll just let you know that the quote I'm tired of terror and despair comes from the work of a poet named Marilyn Hacker. And if you're interested, her poetry in general is very moving and powerful, but she herself is a breast cancer survivor and has a collection called cancer winter, which I highly recommend. And this poem has a pantoum, which is a kind of poem in quatrains, four lines per stanza, where the second and fourth lines of one stanza are then echoed as the first and third in the next stanza. So you'll hear a lot of repetition. It's called I'm Tired of Terror and Despair.

I'm tired of terror and despair and having to be brave. I want the dull unmarked life with eyelashes and hair. I want days and nights that are unexceptional. I don't want to keep on having to be brave. I want the dull of morning honey tea with milk of dishes in the sink. I want days and nights of unexceptional problems like lost keys or pens run out of ink, not like that morning tea untouched by the sink. When I learned I had a problem more grave than pens or keys. I hadn't an inkling when the Oncotype came in, no way to save that dreadful morning.

I had a grave bitter road of brutal loss ahead. The unexpected Oncotype meant I couldn't save either breast, my innocence or the hair on my head. It's never over. The losses still ahead interrupt my work, my love, my sleep, whatever innocence I have left. My head full of the memory of my own warm milk. I weep my love. My work, my sleep will never be free of terror and despair. I piled milky dishes in the sink. I weep, I weep. Don't be fooled into thinking mine is an unmarked life with eyelashes and hair.

Melissa Rosen:

Wow, thank you for sharing something so personal and so strong and so impactful. That really moved me. As Maya continues to share her music and

poetry and a bit of her story, including what surprised her on the path to healing and what helped, please give some thought about what surprised you, what provided you strength, comfort in healing. We've definitely discussed this before. It's so important. Healing from cancer, that experience is physical. We know this. And it's also emotional. Eventually that becomes clear too. For some, it is also spiritual. How has cancer impacted my place in the world? My priorities, my commitments.

The cancer experience itself can include all three aspects, physical, emotional, and spiritual. So it only stands to reason that the healing process will contain those aspects as well. If you are comfortable, please share your thoughts in the chat box about what surprised you most about the healing process. What helped you unexpectedly? It could be the physical healing. We encourage also emotional and spiritual healing. Now we're going to play a song, Maya's song, called Rafino. Once we've heard it, Maya will speak about the meaning of the song and how writing it was a healing experience in and of itself.

(singing).

Maya:

Hi, I'm Maya. I can't see all your faces, but I'm imagining all of your faces and I'm grateful you're all here. And [inaudible 00:14:39] I want to say again to all of you, how grateful I am for your support. And I want to also thank my family and my friends. I have a mentor who says that adulting doesn't mean that you face things alone once you reach a certain age. It means that you know who to ask for help and how to ask for help and when to ask for help. And there's no question that the humility of needing so much help throughout my cancer journey has been a reminder of what a blessing it is when you ask for help and you feel so alone and so afraid to have somebody answer that help. So I'm grateful to be sharing some of my journey with you.

And I realize as I'm beginning to talk with you that this is my first time really talking about my cancer experience. So I'm feeling that sense of nervousness. And I think that I'm sharing that it's my first time talking about it because I've noticed as I've progressed into survivorship, whatever that part of the journey means, that in some ways it feels easier to stuff the cancer experience into a bag, tie it up in knot, put at the bottom of a closet, under lots of stuff and to move on, right? My hair has grown back and my eyelashes. And I'm still undergoing hormone therapy. I was diagnosed two years ago. But in many ways I feel back, whatever back means, right, to normal life. And I think we face this actually also with COVID. I want to encourage myself and maybe all of us not to feel the need to go back. Not to go back, but to go forward. And sometimes that's harder and more painful.

So I want to share a little bit about my cancer journey. And then as Melissa was saying, how writing and music have really helped me on my healing path. So I was diagnosed with stage two breast cancer two years ago in August of 2019. I was 41 years old. I actually found the lump on my own and went to get it checked out on the afternoon that my family was supposed to fly to Israel for

two bar mitzvahs. And I told my daughter who was busy packing, I'll be home in half an hour. Just running out to an appointment. I'll be back. And as it became clear that something was going on and I went from one office to another office and they were actually able to do a lot of the testing, even the biopsy that day. I ended up staying probably seven or eight hours.

She kept texting me. What should I pack? How come you're not home? And this thing that, I have this memory of sort of falling into, at the time I thought it was the Twilight zone where it's something that normally would bother me like an appointment taking an extra hour, in my busy life, which would drive me crazy, suddenly that didn't matter. And it didn't matter that we had to cancel flights that we had bought months before, and rearrange our entire schedule. I was suddenly operating and my family was suddenly operating on an entirely different plane of existence.

And I think at the time, and even in the beginning, when I was making all these decisions and meeting doctors, I felt like, okay, I'm operating in this weird Twilight zone area, but soon I'll come back to the normal plane of life. And as I had to face all of the different aspects of my treatment, I had a double mastectomy. And as you heard from the poem, my Oncotype was higher than we had hoped, which meant that I needed chemo. And I did ACT chemo, 16 rounds, 12 Taxol, and four of the AC. I had a cold cap that kept a lot of my hair for a lot of that time. And now I'm doing hormone therapy.

And as I progressed through that experience, I realized that this normal plane of life was just one plane of life. And it wasn't that I had dropped into this not normal plane of life for this Twilight zone, but that I had simply entered another corridor through which we can walk through the world. And I stopped wanting to go back to that first corridor. Of course I wanted to be healthy. But I think for the first time in my life, I was forced to face stillness, to face quiet. I have five children. My husband [inaudible 00:19:50] is here on the call by my side the whole time. And as we all know, the people we love go through this journey with us. And I really feel that there was a blessing in facing the quiet and being thrust into this other corridor.

I spent time meditating and doing visualizations and taking walks. And I'm the kind of person who is an athlete. And usually I run and I'm fast and I'm doing a million things. And I did so much less. And that's when the music and the poetry started coming through me. And I really felt that it came through me, the music in particular. I've always played the piano. But I would sit at the piano and I would hear music and I would play it. And I felt that I had gotten quiet enough to hear so much of what was actually always inside me. So I think of less that the illness and the treatment and the suffering resulted in creativity. And it's more that the illness and the suffering and the treatment and the pain opened another aspect of living. It was another experience in life.

And by opening that particular aspect of living, other aspects of my life were forced to quiet down. And in the quiet I met a deeper part, or maybe even a

more true or a more real part of who I am, and allowed it to come through. And choosing to hear it was also a choice. I think that I could have gotten busy or I could have made more noise. And it felt very frightening to listen to those songs and then to capture them on my little iPhone when I was playing the piano. And then the version that you heard was actually recorded with a phenomenal artists named Noah Solomon, which is why the song sounds so incredible. Noah Solomon is a professional Jewish musician. He sings with Soul Farm and he, during the pandemic taught himself to be a producer of music and came with his mask to my house with a contraption that recorded me playing the piano and singing.

And then he left my house, went back to his house and in his living room added guitar and drums and harmonies. So it's really incredible how he really turned these melodies into music. But the ability to quiet ourselves enough to hear it, honor what's coming through us and then being willing to share it, I think is part of that living in that vulnerable space that we're forced to live in when we deal with the cancer diagnosis. But I think that's the condition of human life. It's just that it's easier to ignore that condition when we're not facing illness.

So I'll just share that the words of that song [foreign language 00:22:55] come from a traditional Jewish prayer, the [foreign language 00:22:59] prayer, the silent prayer, which is sort of the heart of the daily morning Shahareet service. And [foreign language 00:23:10], the words in that song and in the prayer, [foreign language 00:23:11]. Heal us and we will be healed, save us and we will be saved. And that idea of being in dialogue really spoke to me. I guess, full circle to how I started, that we're not alone. We can feel very alone. Nobody else feels what we feel in our bodies when we go through this experience. And in that sense, we are alone.

But there are so many inner resources we have and so many outer resources we have. And so the [foreign language 00:23:49] that dialogue that back and forth of I am in this with others. Others are affected by this. Others are affecting me. And even when I am most alone, I can reach out and stay connected. That's the prayer I was trying to evoke. So thank you for listening. And I pray for everybody's [foreign language 00:24:12] for everybody's full, complete healing. And for a year of health and wholeness for all the people in this world who need it.

Melissa Rosen:

The people who I work with at [inaudible 00:24:28] will tell you, I'm very rarely without words. But listening to your poetry, your song, and your story has been so impactful to me as a survivor myself. And I am sure to others who are on today's program. We asked people to share a bit about what has been healing for them. And if you still want to share, there's absolutely time to do that. We have a few people in the chat who did share. I'll tell you, including stuff that I wrote. I'm happy to share two things. And then Rachel might share some other things.

I did say that writing was helpful to me, unexpectedly so, and even if you don't consider yourself a writer, I found it helpful. I know journaling works for a lot of people, and that was great. Another thing that really helped me was reimagining and reframing traditional prayer. Whatever faith tradition you come from, just that everything seemed to take on different meetings when I was going through cancer. And so it only stood to reason that prayer were too, And I had to do a lot of reframing and re-imagining to make itself meaningful to me during that time. Rachel, I did see a couple of other things. Would you like to share?

Rachel:

Yes. And I just want to say also, I have a smile on my face only because I am just so amazed by you, Maya. You are just incredible. And I feel honored to know you and have been any part of this experience and journey with you. And really, you just said everything so perfectly, and you're just so relatable and sweet. And I see this message that came in here that somebody wrote that kind of just says it perfectly. They wrote that, they say that we face illness in the exact same way we face the rest of life. And that is why Maya has been healing for me. The honesty, strength, song, creativity, and sensitivity with which she walks this path is a [foreign language 00:26:50] for all of us finding our way. Thank you, dear sweet Maya. And you know what, exactly, that's just the perfect word. So I can understand how you've probably helped many. And you might not even realize.

Another person shared that they found meditation improved their relationship with God. And she said, she heard that when you said, we don't have to walk through this, she heard you, when you said we don't have to walk through this alone. And that is true. I know other women have shared with me as well, even simple things like coloring, drawing, things like that that seems silly. Things you haven't done since you were a child maybe are just this nice peaceful distraction. I know a lot of people share that they find that helpful. And a lot of people also share meditations, which we do have. So if anybody is interested, we have a lot of Sharsheret resources that I, myself, as one of the social workers here at Sharsheret would be more than happy to share with you and help any of you through this journey and this experience as well.

Melissa Rosen:

[inaudible 00:27:52] Rachel. I just want to point out that today we spoke a lot about spiritual healing, and I'm glad because there aren't a lot of places that that type of healing can be done. But there are other types, as well as the reminder and some of the meditations we have are spiritual or even religious in nature and some are absolutely not. So that's more your need at the moment, that's absolutely, we have all different kinds. Before we conclude, I'm excited to be able to have Maya share one additional piece of poetry. This one is called Akeda.

Maya:

Okay. Akeda. And Akeda means sacrifice. And it specifically refers to the binding of Isaac in the Bible. Akeda. This year, not only did I bring you my inner most hopes and fears, my most fervent prayers, my purest voice lifted in song, tears streaming down my cheeks, but also my breasts. I placed them on your crowded

altar, squeezing them in at the edge and wondered if the smell of the blood and the milk and the smoke rising heavenward might be enough for you this year.

Melissa Rosen:

That is also just such amazing imagery and such meaning. Again, not a lot of words. As we conclude, I want to remind you that Sharsheret is here for you. We have many exciting programs being planned, but I want to share two particular things with you today. We're currently recording a social media message for Rosh Hashanah, and it actually sort of is a beautiful segue from all that Maya has shared. For those of you who do celebrate, it will be about actually finding comfort in the Una Tana Tocaf. That is the piece of liturgy for the high holidays that talks about who shall live and who shall die, which is a difficult piece in general, but particularly difficult for those of us who have faced cancer. So be on the lookout for that in a couple of weeks.

And by the way, if you don't follow Sharsheret on social media, this is the perfect time to do so so you don't miss that message. And the other thing I wanted to let you know about is our next Shalom Shabbat program, which is scheduled for Friday, October 6th, and is part of our Sharsheret summit for breast and ovarian cancer awareness month. And we have a really unique program planned for that Shalom Shabbat, a little different than we often do, and registration will be available soon for this event.

And of course our wonderful, dedicated team of social workers, including Rachel and our genetic counselor are here to help you address any concerns. Please don't hesitate to reach out and there'll be contacted information in the chat box. Once again, I want to share my deep thanks to Maya for sharing herself with us today. Right. Not just her poetry and her song, but herself. And I want to thank each and every one of you for joining us today, I am wishing you a Shabbat filled with quiet, with joy and with comfort. A Shabbat filled with Shalom. Thank you very much. Bye bye.

#### About Sharsheret

Sharsheret, Hebrew for "chain", is a national non-profit organization, improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

With four offices (California, Florida, Illinois, and New Jersey), Sharsheret serves 150,000 women, families, health care professionals, community leaders, and students, in all 50 states. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, more than 15% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret's Executive Director chairs the Federal Advisory Committee on Breast Cancer in Young Women, Sharsheret works closely with the Centers for Disease Control and Prevention (CDC), and participates in psychosocial research studies and evaluations

with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

#### The Link Program

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- Embrace<sup>TM</sup>, supporting women living with advanced breast cancer Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer Sharsheret Supports<sup>TM</sup>, developing local support groups and programs

### **Education and Outreach Programs**

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare Professionals

#### Disclaimer

The information contained in this document is presented in summary form only and is intended to provide broad understanding and knowledge of the topics. The information should not be considered complete and should not be used in place of a visit, call, consultation, or advice of your physician or other health care Professional. The document does not recommend the selfmanagement of health problems. Should you have any health care related questions, please call or see your physician or other health care provider promptly. You should never disregard medical advice or delay in seeking it because of something you have read here.

The information contained in this document is compiled from a variety of sources ("Information Providers"). Neither Sharsheret, nor any Information Providers, shall be responsible for information provided herein under any theory of liability or indemnity. Sharsheret and Information Providers make no warranty as to the reliability, accuracy, timeliness, usefulness, or completeness of the information.

Sharsheret and Information Providers cannot and do not warrant against human and machine errors, omissions, delays, interruptions or losses, including loss of data.